

Patients' priorities

Need to be assessed properly and taken into account

Education and debate
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A revolution is under way in health care. After decades of patriarchal provision of services governments are now accepting that patients should have a say in what is provided. Debates on priority setting have brought the case for public participation in difficult healthcare choices sharply into focus.¹ Each new high profile drug launch or controversial therapy spurs further public discussion about what a national health service should provide and who should decide (p 273).² At the level of individual patients there is a growth in demand for information,³ and a review published this week draws attention to the need to improve its quality (p 318).⁴ The launch of a new journal to promote debate about public participation in health care⁵ and the Council of Europe's recommendation that patients must be involved in defining quality of care underline that the movement is gaining momentum.

If services are to be shaped by patients' views, methodologically sound ways of obtaining their views and encouraging people to come forward and present them are needed. It is not easy to get representative views, for all constituencies have their bias and opinions change over time. In all cases, however, providing people with accurate, high quality, up to date information is an important starting point.⁶ Currently various quantitative and qualitative methods of assessing public opinion are used, and increasing credence is being given to the findings of focus groups, deliberative polls, and citizens' juries.⁷

Questionnaire surveys may not rank high as a methodological tool, but it is encouraging that the British government has honoured its pledge to listen to patients by sending questionnaires to 100 000 people to assess their experience of general practice care. Similar surveys are underway to get feedback about cancer and coronary heart disease services, and the results will be published later this year. Meanwhile a European questionnaire survey of 6464 patients in eight countries to determine priorities for primary care has been completed, and the results were aired at a meeting in Copenhagen.⁸

Although the response in the EUROREP study was only 55% and nuances in translation posed some problems, the results suggest that patients across Europe hold remarkably similar views about what they want from primary care services. Top of a list of 38 possible priorities were having enough time in the consultation, being able to get an appointment easily, getting a quick service in an emergency, and having a general practitioner who listens and provides helpful information about patients' illnesses and their treatment and encourages them to discuss all their problems. Also wanted was one who keeps up to date and meets their need for confidentiality and advocacy. The convenience and decor of the medical environment were consistently rated low priorities, and time spent in waiting rooms was seen as much less important than the quality of the consultation.

These findings are salutary. Few of the many changes imposed on primary care in the United Kingdom over the past few years have really taken these central priorities into account, and for a "caring profession" to fail to take adequate account of the priorities of those it exists to serve is hard to justify. It also makes little sense from a medical or economic standpoint. Evidence suggests that where patients are informed and supported to participate in decisions healthcare outcomes are better, services are used more appropriately, patient satisfaction is higher, and there is less risk of litigation.^{9,10} "User involvement" is also a very effective way of improving services.

While these surveys are welcome, it is evident that one off assessments of patients' views and experience of existing services are not enough. Research should be conducted to find out what patients want in the first place. This should then be taken into account in service development, and then the effects of doing so assessed. Repeated evaluation of patients' views of both primary care and hospital services, using validated instruments, should become an integral part of routine care. They could also be used as a benchmark to compare the quality of services between providers. Defining good quality care is notoriously difficult, but any attempt at definition should incorporate patients' views.¹¹

Listening to patients and responding to their needs helps break down the wall between patients and professionals. "Patients always have important insights and priorities that doctors and other health professionals miss," said Professor Tom Delbanco, professor of medicine at Harvard Medical School. "Research on their views and on patient-doctor interaction and shared medical decision making must be recognised as mainstream." The medical mindset needs radical re-adjustment, it was argued forcibly, to accept that patients are partners and that their input into medical education, service provision, research, and policy making is essential.

Tessa Richards *Associate editor, BMJ*

"Patients are partners" will be the subject of a theme issue of the *BMJ* next summer. The guest editor is Angela Coulter. Contributions in the form of papers, editorials, or debate pieces are invited, and should reach us by the end of May 1999.

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- 3 Richards T. Partnership with patients. *BMJ* 1998;316:85-6.
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